

Original Article

The Need for Palliative Care in Ireland: A Population-Based Estimate of Palliative Care Using Routine Mortality Data, Inclusive of Nonmalignant Conditions

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Abstract

Context. Over the history of palliative care provision in Ireland, services have predominantly provided care to those with cancer. Previous estimates of palliative care need focused primarily on specialist palliative care and included only a limited number of nonmalignant diseases.

Objectives. The primary aim of this study was to estimate the potential population with generalist and/or specialist palliative care needs in Ireland using routine mortality data inclusive of nonmalignant conditions. The secondary aim was to consider the quality of Irish data available for this population-based estimate.

Methods. Irish routine mortality data (2007–2011) were analyzed for malignant and nonmalignant conditions recognized as potentially requiring palliative care input, using specific International Statistical Classification of Diseases and Related Health Problems-10th Revision codes. The method developed by Murtagh et al. was used to give a population-based palliative care needs estimate, encompassing generalist and specialist palliative care need.

Results. During the period 2007–2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from noncancer conditions. The majority of deaths, 81% (91,914), were among those ≥ 65 years. There was a 13.9% (901) increase in deaths of those ≥ 85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%).

Conclusion. Future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease and associated palliative care need. New models of palliative care may be required to address this. *J Pain Symptom Manage* 2015;49:726–733. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, terminal care, end-of-life care, needs assessment, public health, chronic illness, Ireland

Introduction

In Ireland in 2011, one in 10 (11%) of the population were aged 65 years or older. This number is projected to double to 22% by 2041,¹ as the proportion

of those aged 65 years or older is increasing in Ireland at the fastest rate in the European Union.² It is internationally recognized that the prevalence of advanced chronic conditions increases with older age. Consistent

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with these international findings, health care service use in Ireland has been shown to increase with age, particularly for those aged 70–80 years.^{3,4} The needs of the aging Irish population may be further complicated as it has been projected that by 2021, 30% of those ≥ 65 years will be living alone.⁵ As a lack of community support is an indicator for hospital death,⁶ these projections may signal an early alert for planning and commissioning consideration for hospital services in the future. Already, in 2006, 48% of deaths in Ireland occurred in hospitals.⁷

Specialist palliative care has been shown to decrease hospital admissions in the last year of life⁸ and increase the odds of home death,⁹ and its effectiveness in improving symptoms and quality of life has been demonstrated.^{10,11} The potential role of palliative care in improving quality of life and symptom control for individuals with diagnoses other than cancer is internationally recognized.^{12–14} Similar to the U.K., palliative care in Ireland is provided to eligible patients in addition to any ongoing medical care at no cost to the patient. However, there is a paucity of Irish data available to determine palliative care needs in the population. This limits health care commissioning future planning and delivery for this important population.^{15,16} This lack of data is evident despite the availability of clear operational definitions between generalist and specialist palliative care in Ireland, which should facilitate the quantification of these palliative care needs. Within the Irish context, generalist palliative care is defined as care provided by health care professionals who apply the principles of palliative care.¹⁷ Specialist palliative care is defined as interdisciplinary care provided under the direction of a consultant physician in palliative medicine.¹⁷ The National Advisory Committee on Palliative Care, in its 2001 report, described the minimum service requirements for specialist palliative care provision,¹⁸ but these are yet to be delivered on. Similar to the U.K., the funding for palliative care in Ireland comes from particularly diverse sources, with major charitable sector funding and variable statutory funding; this range of funding sources makes it challenging to systematically understand and quantify gaps in resourcing.¹⁹ Annually, there is an approximate €70 million deficit in the budget for specialist palliative care, amounting to a 49% shortfall compared with recommended levels.²⁰

For national and regional service planning and development, it is essential to know the numbers in a population who need palliative care, with need here being defined as “the ability to benefit from palliative care.”^{21,22} The benefits of a population-based approach have been internationally recognized, with different approaches using routine mortality statistics to estimate population-based palliative care needs developed in Australia, Spain, and the U.K.^{23–26}

Higginson²⁵ undertook one of the first population-based palliative care needs assessments in the 1990s, where deaths from cancer and six nonmalignant disease groups were multiplied by symptom prevalence.²⁴ However, nonmalignant conditions such as dementia or stroke, more lately recognized as having palliative care needs, were not included.²⁴ In 2005, Rosenwax et al. identified 10 conditions (cancer and noncancer) known to have palliative care needs, using the International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10), and suggested three estimates of potential palliative care need. The minimal estimate was derived from the 10 identified conditions, including Alzheimer’s disease but excluding stroke. The midrange estimate incorporated hospital admissions for any of these 10 conditions (including Alzheimer’s disease and stroke) in the year before death and the maximal estimate included all but sudden deaths, that is, apart from those attributed to injury, poisoning, maternal, perinatal, and neonatal deaths.^{23,27} In 2012, Gomez-Batiste et al.^{26,28} turned the focus to patients with chronic progressive diseases and a limited life prognosis, estimating that these accounted for 75% of all deaths. Of late, Murtagh et al. compared and further developed approaches to needs assessment²³ to both broaden and refine the ICD-10 codes identified to more comprehensively encompass those diagnoses, particularly nonmalignant conditions, that are recognized as commonly having palliative care needs.²⁴ The *Global Atlas of Palliative Care* based its needs assessment on the original approach by Higginson, thus including noncancer conditions, and references the approach by Murtagh et al. as a useful method to identify potential palliative care need.²⁹

Death certification data are available in Ireland. Therefore, we aimed to apply the most recent method to estimate need (developed by Murtagh et al.) to determine a population-based estimate of palliative care need in Ireland. The second aim was to consider the quality of the Irish data available for population-based estimates of palliative care need. Such information will aid future commissioning, planning, and palliative care service development.

Methods

Design

This was a secondary analysis of death registration data. Four estimates may be calculated using the method developed by Murtagh et al.:²⁴ a minimal estimate based on the number of deaths from the conditions identified as having palliative care needs (Table 1); a lower intermediate estimate that includes all deaths in the minimal estimate together with deaths where Alzheimer’s disease, dementia, or

Table 1
ICD-10 Codes for Conditions Identified as Potentially Having Palliative Care Needs

Cause of Death	ICD-10 Codes
Malignant neoplasm	C00–C97
Heart disease, including cerebrovascular disease	I00–I52, I60–I69
Renal disease	N17, N18, N28, C64, I12, I13
Liver disease	K70–K77
Respiratory disease	J06–J18, J20–J22, J40–J47, and J96
Neurodegenerative disease	G10, G20, G35, G122, G903, G231
Alzheimer's, dementia and senility	F01, F03, G30, R54
HIV/AIDS	B20–B24

ICD-10 = International Statistical Classification of Diseases and Related Health Problems-10th Revision.
 Reproduced from Murtagh et al.

senility or renal disease was recorded as a contributory cause; an upper intermediate estimate that includes all deaths where any of the conditions identified in the minimal estimate was mentioned as a contributory cause; and a maximal estimate, which includes all deaths apart from poisoning, injury, and maternal, neonatal, or perinatal deaths.^{23,24} Using the identified ICD-10 codes, this method was applied to the routine mortality statistics available from the Irish Central Statistics Office (CSO) to identify deaths from palliative care-relevant conditions.

Data

The CSO has been using the ICD-10 to code causes of death since 2007;³⁰ hence, data from 2007 until

2011 inclusive were considered³⁰ as this was the most recent data available. On the death certificate, the underlying cause of death is defined as the disease or injury that initiated the chain of events directly linked to death or the circumstances of the accident or violence that produced the fatal injury. The contributory cause of death is defined as a significant condition that influences the course of events and contributes to the death but is not related to the disease or condition causing death.³⁰ The CSO records one cause of death for each individual, which is usually the underlying cause of death.³⁰ The contributory cause of death is not routinely recorded by the CSO.³⁰

Using the death registration data from 2007 to 2011 inclusive from the CSO, the minimal estimate was calculated (Appendix, available at jpsmjournals.com). This is based on the number of deaths from the conditions identified as having palliative care needs (Table 1). Because of the data limitations, it was not possible to apply the other methods described by Murtagh et al.²⁴ to further refine estimates for the Irish population as the contributory cause of death is not routinely recorded and there is no linkage of hospital data with mortality data.

Ethics

On advice from the CSO, it was not necessary to obtain ethical approval for this study as it involved analysis of anonymized secondary data, which are readily available on request.

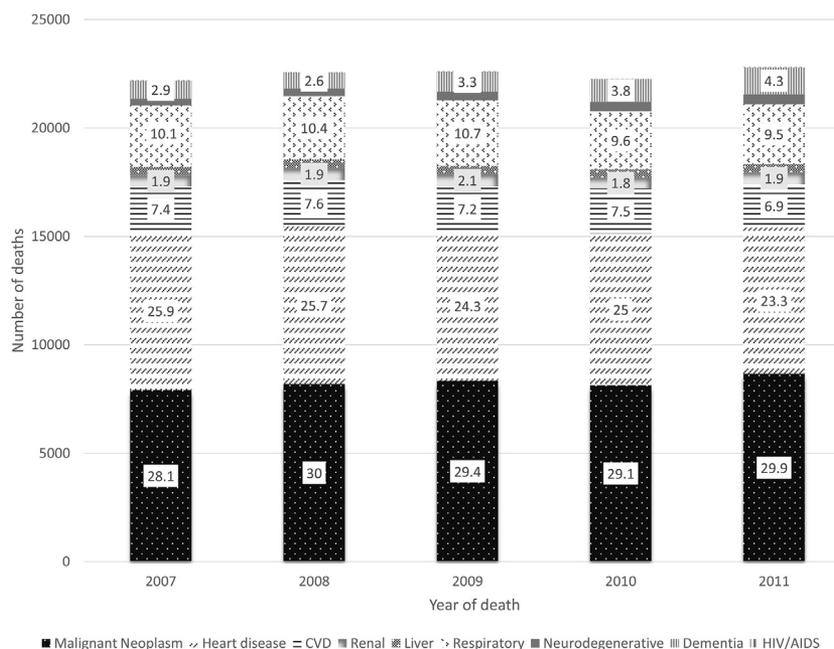


Fig. 1. Deaths in Ireland by conditions with potential palliative care needs according to ICD-10 grouping 2007–2011 (n, %). Bar number = percent proportion. CVD = cerebrovascular disease.

Results

The findings (Fig. 1) show 1475 more deaths in 2011 from cancer than in 2007, increasing from 7197 in 2007 to 8666 in 2011, a proportional increase of 18.6% over the five year period. In 2007, cancer accounted for 28.1% of all deaths, increasing to 29.9% in 2011. Between 2007 and 2011, there were 561 fewer deaths from heart disease (7303–6742) and 85 fewer deaths from cerebrovascular disease (2078–1993), a proportional decrease of 7.7% and 4.1%, respectively, in the absolute number of deaths. Heart disease deaths decreased from 25.9% of all deaths in 2007 to 23.3% in 2011. Cerebrovascular disease deaths fell from 7.4% to 6.9% over the same time frame. Deaths from respiratory disease decreased from 2840 in 2007 (10.1% of all deaths) to 2769 (9.5% of all deaths) in 2011. There was no change in the proportion of deaths from renal disease or HIV/AIDS (Fig. 1). The proportion of total annual deaths over 2007–2011 from conditions with potential palliative care needs, according to the ICD-10 disease grouping, together with the absolute numbers, is shown in Figure 1. The total number of deaths from conditions associated with palliative care needs encompasses 80% of the total deaths annually in Ireland.

There has been a 42.8% increase in the number of deaths from neurodegenerative conditions over the same five year period, from 320 in 2007 to 457 in 2011. The number of deaths from dementia rose steadily, from 827 in 2007 to 1241 in 2011, a 51.3% increase over the five year period.

Most deaths among those with palliative care needs were among those ≥ 65 years, a proportion (82%) that remained constant over the five year period. There was a 13.9% (901) increase in deaths of those

≥ 85 years over the five years. Figure 2 illustrates the comparison between 2007 and 2011 of causes of death according to the ICD-10 grouping in those ≥ 65 years. There was a marked increase in the number of deaths from dementia (826 in 2007 to 1201 in 2011) and neurodegenerative conditions (217 in 2007 to 385 in 2011), as well as cancer (5725 in 2007 to 6315 in 2011) in those ≥ 65 years, with a smaller increase in renal disease as a cause of death (416 in 2007 to 469 in 2011). There were no deaths from HIV/AIDS in this age group.

Discussion

The estimated level of palliative care need in Ireland is considerable; the same estimates (minimal estimates) in Australia (50%)²³ and the U.K. (63%)²⁴ are also significant. Annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs. This higher proportion may be the result of the rapidly aging population,² particularly evident in the 13.9% increase of deaths among those ≥ 85 years. Given these findings, Ireland would appear to have the most rapidly rising need for palliative care in Europe. The number of deaths from cancer is increasing in line with international findings.³¹ Our findings also show that deaths from neurodegenerative conditions increased over the five year period studied. Although in other jurisdictions, this increase can be attributed to a change in the classification of the underlying cause of death,³² this is not the situation in Ireland, where the same classification system was used throughout 2007–2011, the ICD-10. There also has been an increase in deaths from dementia. These findings are of national importance given the previous emphasis on malignant disease in Irish

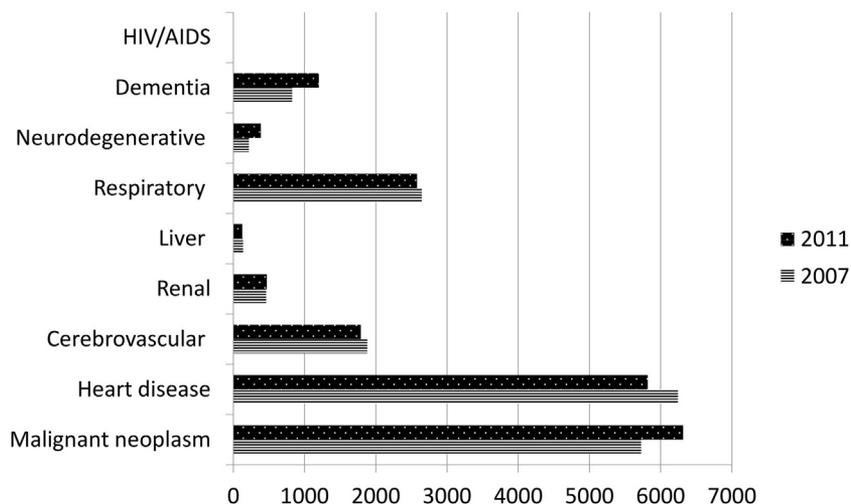


Fig. 2. 2007/2011 Comparison of absolute number of deaths according to ICD-10 grouping in those ≥ 65 years.

palliative care estimates.³³ The increase in cancer as a cause of death is likely to continue, given that the incidence of cancer diagnoses in Ireland is predicted to double by 2040.³⁴ Very importantly, our estimate has revealed that both the numbers of deaths from cancer and noncancer conditions are increasing. This presents a challenge to palliative care in Ireland, to meet both the increasing cancer need and to provide appropriate support to those with nonmalignant conditions. Our estimate has revealed a requirement to equip services for increased numbers of patients with neurodegenerative diseases in a country with one of the fastest aging demographics in Europe.

The current model of palliative care in Ireland is one that primarily provides care to those with cancer. This is the case in palliative care internationally, despite calls for palliative care services to be extended to those with advanced, progressive, chronic conditions with a limited prognosis.^{28,35,36} These findings are particularly useful as they provide an invaluable reference point from which to identify the different models of generalist or specialist palliative care that may benefit these patients. The current emphasis on cancer care in Ireland is comparable to challenges faced by other nations, for example, efforts to change this are underway in the U.K. Given the rapidly aging demographic in Ireland, the solution that is implemented in this country has the potential to assist other countries whose populations are aging less rapidly.

Our study is also important in that it highlights a need for improved linkage of routinely collected data in Ireland. In comparison with the U.K., Irish mortality data are limited as contributory causes of death are not collated by the CSO, impeding a more comprehensive analysis. Because of the lack of a patient unique identifier, no linkage exists with hospital inpatient data or place of death data. The recent publication of the Health Identifiers Bill 2013,³⁷ which includes the creation of Individual Health Identifiers for Irish health care users, will be invaluable in improving the richness of health care data available. We acknowledge that patient unique identifiers must be introduced in a manner so as to respect patient confidentiality.^{38,39} We recommend that future Irish estimates make optimal use of this new change, especially as this will allow cross-national comparisons and cross-national research, which has the potential to further aid national and European Union regional service planning and commissioning.⁴⁰

Despite the new and important findings from this estimate, there are limitations inherent with our method. The primary limitation, as noted by Murtagh et al.,²⁴ is that in using mortality statistics, not all those who die from a particular condition will have had

palliative care needs before death;²⁴ diagnosis does not automatically infer a requirement for palliative care.²⁹ A more complex way of recording and distinguishing generalist and specialist need would allow more detailed estimates. In addition, to demonstrate that there is an actual need for both specialist and generalist palliative care, the demand on services also must be demonstrated in a concrete manner through comprehensive data collection by palliative care services themselves, including outcome data that can give some indication of effectiveness. An example of a solution to this is provided by the Palliative Outcome Collaborative in Australia,⁴¹ which has now begun to be emulated by the Outcome Assessment Complexity Collaborative in the U.K. Such work also may provide data on the trajectory of palliative care need in chronic progressive conditions, information that would greatly enhance the analysis undertaken here as it would allow more accurate descriptions of duration and amount of need over time, to inform future planning of palliative care services. Another limitation with this analysis is that data on comorbidities were unavailable; hence, death is attributed here to one cause only. Comorbidities are common particularly among the elderly population and potentially complicate the illness trajectory. A further limitation is that neurodegenerative conditions may have been underestimated because these are not as well recorded as, for example, cancer, particularly for older people.³² In addition, not all neurodegenerative conditions were included in this analysis.⁴²

The Murtagh et al. method was used here because although the method developed by Higginson²⁵ also uses mortality data adjusted by symptoms to give an estimate of palliative care need, this approach includes a smaller number of nonmalignant conditions,²⁵ thus underestimating the population with palliative care needs. This method excludes dementia, a condition recognized as associated with palliative care needs.^{43,44} In Ireland, it is predicted that there will be a 63% increase in people living with dementia, from 41,477 in 2006 to 67,493 in 2021,⁴⁵ necessitating its inclusion in any palliative care needs assessment. Work has been undertaken to produce a consensus on how to provide palliative care to Irish people living with dementia,^{45,46} and our estimate would be useful to further this national work. The method developed by Gomez-Batiste et al.²⁸ provides a direct measurement at the patient level of the prevalence of advanced chronic conditions, including dementia and stroke, where those affected have palliative care needs. It uses an instrument that involves the imputation of patient data to predict palliative care need and so requires health care professional involvement to assess patients on

an individual level;²⁸ this was not practicable when assessing a population on a national level.

In 2006, the Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland, in calling for increased service provision, estimated that the population with specialist palliative care needs in 2016 would be 12,500, 70% having a cancer diagnosis and 20%–30% having a noncancer diagnosis.³³ This figure is just over half of the estimate for 2011 (23,188) calculated by our analysis. Our analysis differs in that it includes more nonmalignant conditions than previous needs assessments and encompasses both those with specialist and/or generalist palliative care needs. In estimating the need for palliative care, it is necessary to consider both specialist and generalist together as the needs of individuals fluctuate, particularly those with nonmalignant conditions.^{46–48} Also, incorporating both generalists and specialists allows for workforce planning. This is important amid the increased prevalence of chronic disease and the call for integration between specialists and generalists.^{47–49}

Quantifying the population-based need for palliative care in Ireland provides a concrete starting point to illustrate to policy makers the future service requirements and that palliative care necessitates secure funding.^{15,16} Our estimate brings us one step closer toward addressing the requirement for data to illustrate the gap between existing need and palliative care funding and service provision in Ireland.^{16,15} In particular, our results highlight the anticipated need of those with neurodegenerative disease. Although the increase in absolute numbers is small for neurodegenerative conditions, these numbers are increasing rapidly. If this increase continues at a similar pace, this will become an important issue.

Conclusion

Our study of palliative care needs over time demonstrates that the number of deaths is increasing, particularly deaths from cancer and neurodegenerative disease. The challenge for health care commissioning and palliative care is how to deal with the steady increase in cancer deaths and this new increase in neurodegenerative conditions. Research is needed to determine the best models of palliative care to support people with neurodegenerative conditions. This analysis emphasizes the necessity for routinely collected data at a patient, service, and population level to inform policy makers of the need for palliative care service delivery and use. An integrated and comprehensive framework of routine outcome data collection would provide pertinent information on the timing, duration, and nature of palliative care need for those

with chronic progressive conditions. This would help ensure effective, timely provision of palliative care services to meet changing population needs.

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Appendix

Formulae for Calculations

$$\text{Annual proportion of deaths from (ICD - 10 disease grouping) for 2007} = \frac{\text{Deaths from (ICD - 10 disease grouping) in 2007} \times 100}{\text{Total number of deaths in 2007}}$$

$$\text{Annual proportion of deaths from (ICD - 10 disease grouping) for 2011} = \frac{\text{Deaths from (ICD - 10 disease grouping) in 2011} \times 100}{\text{Total number of deaths in 2011}}$$

$$\text{Proportional change in deaths from (ICD - 10 disease grouping) from 2007 to 2011} = \frac{[\text{Deaths from (ICD - 10 disease grouping) in 2011} - \text{deaths from (ICD - 10 disease grouping) in 2007}] \times 100}{\text{Total deaths from (ICD - 10 disease grouping) in 2007}}$$

Malignant Neoplasm (C00–C97)

Annual Proportion of Deaths for 2007	Annual Proportion of Deaths for 2011	Proportional Change in Deaths From 2007 to 2011
28.1%	29.9%	18.6%
Heart Disease (I00–I52)		
Annual Proportion of Deaths for 2007	Annual Proportion of Deaths for 2011	Proportional Change in Deaths From 2007 to 2011
25.9%	23.3%	7.7%
Cerebrovascular Disease (I60–I69)		
Annual Proportion of Deaths for 2007	Annual Proportion of Deaths for 2011	Proportional Change in Deaths From 2007 to 2011
7.4%	6.9%	4.1%
Neurodegenerative Disease (G10, G20, G35, G122, G903, G231)		
Annual Proportion of Deaths for 2007	Annual Proportion of Deaths for 2011	Proportional Change in Deaths From 2007 to 2011
1.1%	1.6%	42.8%
Alzheimer's Disease, Dementia, Senility (F01, F03, G30, R54)		
Annual Proportion of Deaths for 2007	Annual Proportion of Deaths for 2011	Proportional Change in Deaths From 2007 to 2011
2.9%	4.3%	50.1%

ICD-10 = International Statistical Classification of Diseases and Related Health Problems-10th Revision.